

Manuscript Number: JAMDA-D-13-00342R1

Title: A Comparative Analysis of Comprehensive Geriatric Assessments for Nursing Home Residents Receiving Palliative Care: a Systematic Review

Article Type: Review Article

Keywords: Comprehensive geriatric assessments; Palliative care; Older adults; Nursing homes.

Corresponding Author: Ms. Kirsten Hermans, Jr.

Corresponding Author's Institution: KU Leuven

First Author: Kirsten Hermans, MSPsy

Order of Authors: Kirsten Hermans, MSPsy; Johanna De Almeida Mello, MSEcon; Nele Spruytte, MSPsy, PhD; Joachim Cohen, MSSoc, PhD, Professor; Chantal Van Audenhove, MSPsy, PhD, Professor; Anja Declercq, MSSoc, PhD, Professor

Abstract: ABSTRACT

Background/objectives: Nursing homes become important locations for palliative care. By means of comprehensive geriatric assessments (CGAs), an evaluation can be made of the different palliative care needs of nursing home residents. This review aims to identify all CGAs that can be used to assess palliative care needs in long-term care settings and that have been validated for nursing home residents receiving palliative care. The CGAs are evaluated in terms of psychometric properties and content comprehensiveness.

Design: A systematic literature search in electronic databases MEDLINE, Web of Science, EMBASE, Cochrane, CINAHL and PsycInfo was conducted for the years 1990 to 2012.

Setting: Nursing homes.

Participants: Nursing home residents with palliative care needs.

Measurements: Psychometric data on validity and reliability were extracted from the articles. The content comprehensiveness of the identified CGAs was analyzed, using the 13 domains for a palliative approach in residential aged care of the Australian Government Department of Health and Ageing (AGDHA).

Results: A total of 1368 articles were identified. Seven studies met our inclusion criteria, describing five different CGAs that have been validated for nursing home residents with palliative care needs. All CGAs demonstrate moderate to high psychometric properties. The interRAI Palliative Care instrument (interRAI PC) covers all domains for a palliative approach in residential aged care of the AGDHA. The McMaster Quality of Life Scale (MQLS) covers nine domains. All other CGAs cover seven domains or fewer.

Conclusion: The interRAI PC and the MQLS are considered to be the most comprehensive CGAs to evaluate the needs and preferences of nursing home residents receiving palliative care. Future research should aim to examine the effectiveness of the identified CGAs and to further validate the CGAs for nursing home residents with palliative care needs.

# **A Comparative Analysis of Comprehensive Geriatric Assessments for Nursing Home Residents Receiving Palliative Care: a Systematic Review**

## Running title

CGAs for palliative care in nursing homes

## Key words

Comprehensive geriatric assessments, Palliative care, Older adults, Nursing homes

## Authors

1. Kirsten Hemans, MSPsy,<sup>a</sup>
2. Johanna De Almeida Mello, MSEcon,<sup>a</sup>
3. Nele Spruytte, MSPsy, PhD,<sup>a</sup>
4. Joachim Cohen, MSSoc, PhD, Professor<sup>b</sup>
5. Chantal Van Audenhove, MSPsy, PhD, Professor<sup>a</sup>
6. Anja Declercq, MSSoc, PhD, Professor<sup>a</sup>

<sup>a</sup>LUCAS, Center for Care Research and Consultancy, KU Leuven, Kapucijnenvoer 39 / 5310 B-3000 Leuven

<sup>b</sup>End-of-Life Care Research Group, Vrije Universiteit Brussel & Ghent University, Laarbeeklaan 103 B-1090 Brussels

## Corresponding author

Kirsten Hemans

Address: LUCAS, Center for Care Research and Consultancy, KU Leuven, Kapucijnenvoer 39 / 5310 B-3000 Leuven, BELGIUM

Phone: +32 16 33 64 75

Fax: +32 16 33 69 22

Email address: Kirsten.Hemans@med.kuleuven.be

## Alternate corresponding author

Anja Declercq

Address: LUCAS, Center for Care Research and Consultancy, KU Leuven, Kapucijnenvoer 39 / 5310 B-3000 Leuven, BELGIUM

Phone: +32 16 33 69 18

Fax: +32 16 33 69 22

Email address: Anja.Declercq@med.kuleuven.be

## Funding Source

The study is part of 'Flanders Study to Improve End-of-life Care and Evaluation Tools' (FLIECE), a collaboration between VUB, UGent, KU Leuven and VUmc Amsterdam. This project is funded by the Agency for Innovation by Science and Technology (SBO IWT nr. 100036).

# A Comparative Analysis of Comprehensive Geriatric Assessments for Nursing Home Residents Receiving Palliative Care: a Systematic Review

## ABSTRACT

**Background/objectives:** Nursing homes become important locations for palliative care. By means of comprehensive geriatric assessments (CGAs), an evaluation can be made of the different palliative care needs of nursing home residents. This review aims to identify all CGAs that can be used to assess palliative care needs in long-term care settings and that have been validated for nursing home residents receiving palliative care. The CGAs are evaluated in terms of psychometric properties and content comprehensiveness.

**Design:** A systematic literature search in electronic databases MEDLINE, Web of Science, EMBASE, Cochrane, CINAHL and PsycInfo was conducted for the years 1990 to 2012.

**Setting:** Nursing homes.

**Participants:** Nursing home residents with palliative care needs.

**Measurements:** Psychometric data on validity and reliability were extracted from the articles. The content comprehensiveness of the identified CGAs was analyzed, using the 13 domains for a palliative approach in residential aged care of the Australian Government Department of Health and Ageing (AGDHA).

**Results:** A total of 1368 articles were identified. Seven studies met our inclusion criteria, describing five different CGAs that have been validated for nursing home residents with palliative care needs. All CGAs demonstrate moderate to high psychometric properties. The interRAI Palliative Care instrument (interRAI PC) covers all domains for a palliative approach in residential aged care of the AGDHA. The McMaster Quality of Life Scale (MQLS) covers nine domains. All other CGAs cover seven domains or fewer.

**Conclusion:** The interRAI PC and the MQLS are considered to be the most comprehensive CGAs to evaluate the needs and preferences of nursing home residents receiving palliative care. Future research should aim to examine the effectiveness of the identified CGAs and to further validate the CGAs for nursing home residents with palliative care needs.

**Abbreviations:** CGAs: Comprehensive Geriatric Assessments / AGDHA: Australian Government Department of Health and Ageing / InterRAI PC: InterRAI Palliative Care / MQLS: The McMaster Quality of Life Scale

**Key words:** Comprehensive geriatric assessments, Palliative care, Older adults, Nursing homes

## INTRODUCTION

In developed countries, an increasing number of older people are dying in long-term care facilities.<sup>1-4</sup> It is estimated that, in Belgium, about 40 percent of all deaths will take place in nursing homes by 2038.<sup>3</sup> In the USA this is estimated to already be the case by 2020.<sup>4</sup> Consequently, nursing homes become important locations for palliative care.<sup>1-4</sup> The Australian Government Department of Health and Ageing (AGDHA) published the first evidence-based guidelines for a palliative approach in residential aged care. Based on a literature review, 13 domains are identified as relevant for a palliative approach in residential aged care: (1) a palliative approach, including care models and care practices; (2) assessment and management tools; (3) co-morbidities; (4) cognitive impairment; (5) physical care; (6) psychosocial support; (7) spiritual support; (8) family or caregiver support; (9) indigenous support (only relevant to certain countries); (10) cultural support; (11) advance care plans; (12) dignity and quality of life; and (13) rural and remote issues.<sup>5</sup>

Optimal palliative care should be comprehensive and requires an appraisal of empirically supported key elements of palliative care.<sup>6,7</sup> In practice however, it is difficult to gather information on all these important domains for each individual.<sup>8</sup>

Comprehensive geriatric assessments (CGAs) are based on the premise that a systematic evaluation may improve diagnostic accuracy, optimize medical treatment, improve prognosis, restore and maximize function, improve quality of life and reduce costs.<sup>9</sup> CGAs systematically collect client's data, assess their health status for existing and potential problems and provide guidance in planning care.<sup>10,11</sup> Thus, by means of CGAs, a suitable evaluation can be made of all essential needs of older persons and their families. Through this evaluation, caregivers can determine what services are necessary to meet their client's needs.<sup>8</sup>

Given that the World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of the patient and his or her family through an early detection of palliative care needs, an impeccable assessment and an impeccable treatment of physical, psychosocial and spiritual domains"<sup>12</sup>, a CGA -in order to be comprehensive- must at least contain the domains 'physical care', 'psychosocial support' and 'spiritual support' of the AGDHA and should preferably cover the different domains that are intrinsic of palliative care.<sup>5</sup>

Although several reviews have been conducted on CGAs for palliative care, these studies are generally concentrated on older adults with advanced cancer who are receiving care at home or in a hospital.<sup>13,14</sup> Other reviews have provided an overview of outcome measures in end-of-life care.<sup>15-16</sup> Parker and Dodkinson have given a summary of palliative care outcome measures for long-term care facilities.<sup>17</sup> Furthermore, a review has been conducted on instruments that measure quality of end-of-life care and quality of dying.<sup>18</sup> To our knowledge, however, no systematic review exists on CGAs that are validated for nursing home residents with palliative care needs.

The aims of this systematic review are twofold: (1) to identify all CGAs that can be used to assess the different palliative care needs in long-term care settings and that have been validated for nursing home residents receiving

66 palliative care; and (2) to evaluate the psychometric properties and the content comprehensiveness of these  
67 CGAs.  
68

## METHODS

### Literature Search Strategy

A systematic literature search in electronic databases MEDLINE, Web of Science, EMBASE, Cochrane, CINAHL and PsycInfo was conducted for the years 1990 to 2012. Two reviewers constructed a comprehensive list of Medical Subject Headings (MeSH) which was designed for 5 explicit categories: (1) comprehensive; (2) geriatric; (3) assessment; (4) palliative care; (5) nursing homes (Table 1).

### Study Selection and Data Extraction

The study was based on the PRISMA guidelines for reporting systematic reviews.<sup>19</sup> Titles and abstracts of all articles were examined by two independent reviewers. Studies were included if they described a CGA which at least contained items on physical, psychosocial and spiritual aspects and if the study cohort was composed of palliative nursing home residents. Only peer-reviewed articles were included.

Exclusion criteria were:

1. Instrument was non-comprehensive. Based on the WHO definition of palliative care<sup>12</sup>, instruments that did not at least contain the domains 'physical care', 'psychosocial support' and 'spiritual support' of the AGDHA were excluded<sup>5</sup>;
2. Studies that focused exclusively on interventions, treatments or trainings and not on assessments;
3. Articles about a non-palliative care population and/or a specific population (e.g. cancer patients, persons with Alzheimer's disease, etc.);
4. Studies that were not conducted in the nursing home setting;
5. Studies about instruments, specifically intended for people in the last hours or days of their lives as our focus was on geriatric assessments at the initiation of palliative care;
6. Articles that were not published in English;
7. And articles that were not a validation study of a CGA for nursing home residents in the palliative phase.

The identified CGAs for palliative care in nursing homes were reviewed by two independent researchers as to content comprehensiveness and psychometric properties. The following data were extracted from studies which evaluated CGAs for nursing home residents receiving palliative care: (1) author; (2) instrument; (3) study design; (4) mean age; (5) sample size; and (6) population of validation process (Table 2). Data from studies which used CGAs in palliative elderly were also extracted: (1) instrument; (2) items; (3) scale; (4) reliability; (5) validity; (6) sensitivity to change; (7) filled out by; and (8) completion time (Table 3). The content comprehensiveness of each instrument was evaluated, based on the 13 domains for a palliative approach in residential aged care of the Australian Government Department of Health and Ageing (AGDHA); the content of each instrument was screened by two independent examiners (Table 4). The decision to select these domains was made after

103 extensive review of the literature on domains within palliative care and a subsequent discussion in a group of 17  
104 researchers, involved in research on palliative care (<http://www.fliece.be/>). We used these domains because they  
105 are more extensive, compared to the eight domains of quality palliative care of the US National Consensus  
106 Project for Quality Palliative Care.<sup>20</sup> Additionally, the domains of the AGDHA are based on a content analysis of  
107 the literature and are specifically aimed at nursing homes.<sup>5</sup>  
108



## RESULTS

A total of 1339 articles were identified in the original literature search (Figure 1). An additional 29 articles were identified through a combination of hand searching of journals and snowball searching on the references cited in the papers that were identified by the search. Twenty-four duplicates were removed, resulting in 1344 articles that were screened for inclusion. Subsequently, 176 full-text articles were assessed for eligibility and seven articles met the inclusion criteria, describing five different CGAs for nursing home residents receiving palliative care: Missoula-Vitas Quality of Life Index-Revised (MVQOLI-R), modified Quality of Life Concerns in the End of Life Questionnaire (mQOLC-E), McMaster Quality of Life Scale (MQLS), interRAI Palliative Care (interRAI PC), Palliative care Outcome Scale (POS).

### Missoula-VITAS Quality of Life Index-Revised (MVQOLI-R)

In 2005, the MVQOLI-R was adapted from the Missoula-VITAS Quality of Life Index (MVQOLI) to provide a valuable clinical tool to measure adaptation of people nearing the end of life to physical and functional decline.<sup>21</sup> A second aim of the instrument was to measure the attainment of tasks of life completion and life closure. The MVQOLI-R contains 25 items and includes five subscales: (1) symptoms, (2) function, (3) interpersonal, (4) well-being and (5) transcendence. The instrument has an acceptable internal consistency ( $\alpha = 0.71$ ) and a good test-retest reliability ( $r = 0.77$ ). The MVQOLI-R correlates weakly to moderately with the global Quality Of Life Scale ( $r = 0.35$ ), the Ryff Happiness Scale ( $r = 0.47$ ), the total symptom burden on the Memorial Symptom Assessment Scale ( $r = -0.35$ ) and mood ( $r = 0.46$ ). Concurrent validity data on the MVQOLI are not reported. The total score on the MVQOLI-R has an impact on global symptom related distress after adjusting for mood (Table 3). The MVQOLI-R is not psychometrically robust but performs very well as a clinical tool for stimulating communication about psychosocial and spiritual issues and to understand patient's needs. This tool might advance patient-centered palliative approaches in the early stage of the illness.<sup>21</sup> Seven domains of the guidelines for a palliative approach in residential aged care of the AGDHA are covered by the MVQOLI-R (Table 4).<sup>5</sup>

### Modified Quality of Life Concerns in the End of Life Questionnaire (mQOLC-E)

The Quality-of-life Concerns in the End of Life Questionnaire (QOLC-E) was originally designed to evaluate quality-of-life concerns of patients with chronic obstructive pulmonary disease and terminal cancer. In 2008, the QOLC-E was adapted for frail older nursing home residents in need of palliative care.<sup>22</sup> This modified QOLC-E (mQOLC-E) is a 23-item instrument which consists of six subscales: (1) value of life, (2) care and support, (3) food-related concerns, (4) negative emotions, (5) physical discomfort and (6) existential distress. It takes about 20 to 60 minutes to fill out the mQOLC-E. The instrument shows high internal consistency ( $\alpha = 0.89$ ) and good inter-rater reliability ( $r = 0.83$ ). The mQOLC-E is significantly correlated with the Single-Item Quality of Life Scale (SIS) ( $r = 0.60$ ,  $p \leq 0.001$ ) and weakly but significantly correlated in a negative way with the Cumulative Illness

Rating Scale (CIRS) ( $r = -0.14$ ,  $p=0.013$ ). While conclusions are drawn from a cross-sectional study, sensitivity cannot be assumed (Table 3). The mQOLC-E is a valid and reliable questionnaire to assess quality-of-life concerns of older nursing home residents in the palliative phase. However, it has only been culturally validated for Chinese older people.<sup>22</sup> Six domains of the guidelines for a palliative approach in residential aged care of the AGDHA are covered by the mQOLC-E (Table 4).<sup>5</sup>

#### **McMaster Quality of Life Scale (MQLS)**

The MQLS was developed at the McMaster University in Canada by reviewing the palliative care literature for suitable items and dimensions.<sup>23</sup> The 32-item instrument includes physical symptoms, functional status, social functioning, emotional status, cognition, sleep and rest, energy and vitality, general life satisfaction and meaning of life. Research findings suggest that the MQLS has good psychometric properties. The MQLS shows good internal consistency ( $\alpha = 0.80$ ), a high intra-rater reliability ( $r \geq 0.83$ ) and a moderate inter-rater reliability ( $r = \geq 0.55$ ). As hypothesized, verbally administered scores are lower than scores of self-completers ( $t = 1.83$ ,  $p = 0.04$ ). The instrument has been validated with the Spitzer Quality of Life Index (SQLI). The staff-MQLS was highly correlated with the SQLI ( $r = 0.70$ ) and the patient-MQLS was moderately correlated with the SQLI ( $r = 0.50$ ). These findings show evidence of concurrent validity. Furthermore, the scale is sensitive to change in the condition of the patient (Table 3). The tool is reliable and valid to assess quality of life during the period of palliative care. In addition, the MQLS assesses the quality of life from the perspective of the patient to maintain the patient as informant about his or her own quality of life as long as possible.<sup>23</sup> The MQLS covers nine domains of guidelines for a palliative approach in residential aged care of the AGDHA (Table 4).<sup>5</sup>

#### **InterRAI Palliative Care (interRAI PC) - former Minimum Data Set (MDS)**

The multinational research collaboration InterRAI ([www.interRAI.org](http://www.interRAI.org)) has developed the interRAI suite of instruments (Long-term Care, Home Care, Mental Health, Intellectual disability, Acute Care, Palliative Care, etc.) to support assessment and care planning in aged care, mental health and services for people with disabilities. Every interRAI-instrument includes a questionnaire, consisting of questions about the care context of the client. Results are calculated by means of internationally validated algorithms. Examples of results are the CAPs (Client Assessment Protocols), the Scales and the QIs (Quality Indicators). Based on these outcomes, individual care plans can be evaluated and adjusted.<sup>24,25</sup> In Belgium, the interRAI suite of instruments can be linked and filled out on a free online web application ([belrai.org](http://belrai.org)).<sup>26</sup> The interRAI suite of instruments improves the transfer of information between caregivers and health care settings and demonstrates compatibility of items and results to ensure continuity of care.<sup>27,28</sup> Furthermore, research has shown that the interRAI suite of instruments may improve the quality of care in nursing homes and enhances outcomes for nursing home residents.<sup>29-31</sup> The interRAI Palliative Care (interRAI PC) instrument is a holistic and standardized assessment instrument to

177 evaluate the needs, strengths and preferences of palliative care patients in all settings. The 74-item instrument is  
178 divided in 17 sections and is validated for nursing home residents with palliative care needs. Despite the number  
179 of items, the instrument only takes 20 minutes to fill out (login time excluded). However, completion time depends  
180 on the amount of detail that is required about a certain domain.<sup>32</sup>

181 The interRAI PC was assessed in two study populations, including nursing home residents with palliative care  
182 needs (Table 2).<sup>32,33</sup> The inter-rater reliability was greater than 0.77 in all domains (average Kappa = 0.83). The  
183 Kappa value was 0.80 or higher for about 50 percent of the questions (Table 3).<sup>32,33</sup> However, no data on other  
184 psychometric properties of the interRAI PC have been reported in these articles.<sup>32,33</sup>

185 The last version of the interRAI PC (Version 9.1)<sup>34</sup> covers all domains of the guidelines for a palliative approach  
186 in residential aged care of the AGDHA (Table 4).<sup>5</sup>

### 188 **Palliative care Outcome Scale (POS)**

189 The POS was created by Hearn and Higginson in 1999 to assess outcomes in palliative care for patients with  
190 advanced cancer.<sup>35</sup> Later on, the instrument was also used for palliative nursing home residents. There are two  
191 versions of the POS: a POS-Staff version and a POS-patient version. They both have ten items regarding  
192 physical, psychological and spiritual domains of life. These items are scored on a Likert scale. The POS also  
193 contains two open questions on the main concerns of the patient. The POS has a completion time of about 10  
194 minutes. Brandt et al. assessed the POS in 16 Dutch nursing homes.<sup>36</sup> According to the study design, data on  
195 test-retest reliability, inter-rater reliability and internal consistency should be available but these data were not  
196 reported in the article (Table 3). The POS is a suitable instrument to assess cancer and non-cancer and  
197 (moderately) severely demented patients.<sup>35-37</sup> The POS comprises seven domains of the guidelines for a  
198 palliative approach in residential aged care of the AGDHA (Table 4).<sup>5</sup>

## DISCUSSION

This systematic review identified five comprehensive geriatric assessments (CGAs) that were validated for nursing home residents with palliative care needs: the Missoula-VITAS Quality of Life Index – Revised (MVQOLIR); the modified Quality of Life Concerns in the End of Life Questionnaire (mQOLC-E); the McMaster Quality of Life Scale (MQLS); the interRAI Palliative Care instrument (interRAI PC); and the Palliative care Outcome Scale (POS). From a psychometric point of view, the MQLS was validated more thoroughly than the other instruments. However, the interRAI Palliative Care instrument was evaluated as most comprehensive in terms of content.

The content comprehensiveness of a CGA was evaluated based on the 13 domains for a palliative approach in residential aged care of the Australian Government Department of Health and Ageing (AGDHA). Compared to the other instruments, the interRAI PC does not only contain items on physical, psychosocial, spiritual and quality of life aspects, but also on the other domains of the AGDHA.<sup>5</sup> Despite the number of items, the instrument only takes 20 minutes to fill out (login time excluded). However, completion time depends on the amount of detail that is required about a certain domain.<sup>32</sup>

Apart from its advantage in terms of content comprehensiveness, the interRAI PC has a number of other properties that could plead for its use as a CGA. The instrument is considered to be suitable for use in palliative care because, based on the outcomes (CAPs, Scales, QIs), individual care plans can be evaluated and adjusted.<sup>24,25</sup> Consequently, the interRAI PC instrument is also suitable as a management tool.<sup>5</sup>

Furthermore, the interRAI PC instrument is part of the interRAI suite of instruments. In Belgium, the interRAI suite of instruments can be linked and filled out on a free online web application (belrai.org).<sup>27</sup> As the interRAI PC instrument is designed to be used within and across different health care settings (home care, acute care, long-term care, etc.), it can improve the transfer of information between caregivers and health care settings.<sup>27,28</sup> Additionally, the instrument shows high inter-rater reliability.<sup>32,33</sup> Although a number of studies have been conducted on the validity and reliability of the interRAI suite of instruments<sup>32,33,38-47</sup>, other psychometric properties of the interRAI PC have not been examined in nursing homes to our knowledge.<sup>32,33</sup> It has to be acknowledged that this is a limitation of the instrument. The interRAI PC thus requires further psychometric testing for validity in the nursing home setting.

The MQLS is considered to be the second most comprehensive instrument. This instrument contains 32 items and covers nine domains of the guidelines for a palliative approach in residential aged care of the AGDHA (Table 4).<sup>5</sup> The MQLS was broadly validated in the palliative nursing home setting. The instrument shows good internal consistency, high intra-rater reliability and good construct and concurrent validity. The MQLS assesses the quality of life from the perspective of the palliative patient to maintain the patient as informant about his or her own quality of life as long as possible.<sup>23</sup> From a psychometric point of view, the MQLS was validated more

thoroughly than the other instruments. However, based on content comprehensiveness, the MQLS covers fewer domains than the interRAI PC. Items on 'Care models and practices', 'Indigenous support' and Cultural support are lacking in the MQLS (Table 4).<sup>5</sup>

The MVQOLI-R, the POS, and particularly the mQOLC-E were evaluated as less comprehensive CGAs. Additionally, the MVQOLI-R is not psychometrically robust but performs well as a clinical tool for stimulating communication about psychosocial and spiritual issues and to understand patient's needs.<sup>21</sup> Regarding the validity of the POS, only data on content validity were reported.<sup>35-37</sup> Despite it being the least comprehensive CGA, the mQOLC-E is a valid and reliable questionnaire to assess quality-of-life concerns of older nursing home residents in the palliative phase.<sup>22</sup>

Although our study considers interRAI PC and the MQLS to be the most comprehensive instruments, the strengths of the other instruments should not be overlooked. While the interRAI PC is more suitable as a care planning tool, the MQLS, the MVQOLI-R and the mQOLC-E were designed to assess the overall quality of life of palliative care patients.<sup>21-23</sup> These instruments are especially helpful when palliative care is aimed at optimizing the quality of life of the dying person.<sup>18,48</sup> An additional benefit of the MVQOLI-R is that it can be used as a clinical tool to encourage communication about spiritual and psychosocial issues.<sup>21</sup> Finally, the POS is a suitable instrument to assess not only respondents that are cognitively able to participate but also persons with moderate or severe dementia.<sup>35-37</sup>

## **LIMITATIONS**

The present study has a number of limitations that should be considered. Only studies published in English were included. Furthermore, the current review focused on CGAs with a view to improving care planning for older adults in palliative care. As a result, CGAs intended to assess the non-palliative nursing home population were not considered even though these CGAs could also meet some of the goals of palliative care CGAs. It also has to be acknowledged that, as a palliative care CGA should be filled out from the time a person is in need for palliative care, an early detection of patients in need for palliative care is of great importance. General CGAs, not specialized in palliative care, could detect the need for palliative care in an early phase and these instruments could enable care professionals to timely determine whether a palliative care CGA, such as the interRAI PC or the MQLS should be filled out. Finally, the content and validity of the CGAs were analyzed but the effectiveness of each instrument was not explored in detail.

## CONCLUSION AND IMPLICATIONS

Based on this systematic review, five different CGAs that have been validated for nursing home residents with palliative care needs were identified. All CGAs demonstrate moderate to high psychometric properties.

At this moment, we consider the interRAI Palliative Care instrument (interRAI PC) and the McMaster Quality of Life Scale (MQLS) to be the most comprehensive geriatric assessments to evaluate the needs and preferences of nursing home residents receiving palliative care. While the interRAI PC can be used as a management tool to construct a comprehensive plan of care, the MQLS was designed to assess the overall quality of life and is aimed at optimizing the quality of life of palliative care patient.

The MQLS shows strong validity and reliability. The interRAI PC has high inter-rater reliability. However, other data on the psychometric properties of the interRAI PC instrument are not reported. Consequently, further psychometric research needs to be conducted before further statements can be made on the instrument.

Future research should aim to examine the psychometric properties and the effectiveness of all identified CGAs and especially of the interRAI PC. Additionally, future research should aim to determine whether general CGAs, not specialized in palliative care, could detect the need for palliative care in an early phase and if these instruments could enable care professionals to timely determine whether a palliative care CGA, such as the interRAI PC or the MQLS should be filled out.

288 **ACKNOWLEDGMENTS**

289 The authors would like to thank the panel of 17 researchers, involved in research on palliative care, for their  
290 advice and feedback. The authors would also like to thank Prof. Dr. Trevor Smith of the Department of Sociology  
291 at the Nipissing University in Canada.

292

293 The study is part of 'Flanders Study to Improve End-of-life Care and Evaluation Tools' (FLIECE), a collaboration  
294 between VUB, UGent, KU Leuven and VUmc Amsterdam. This project is funded by the Flemish government  
295 Agency for Innovation by Science and Technology (SBO IWT nr. 100036).

296

297 **CONFLICT OF INTEREST**

298 We declare that we have no competing interests.

299

## REFERENCES

1. Davies E, Higginson IJ. *Better palliative care for older people*. Copenhagen, Denmark: World Health Organization, 2004.
2. Percival J, Johnson M. End-of-life care in nursing and care homes. *Nurs Times* 2013;109(1-2):20-22.
3. Houttekier D, Cohen J, Surkyn J, Deliens L. Study of recent and future trends in place of death in Belgium using death certificate data: a shift from hospitals to care homes. *BMC Public Health* 2011;11:228.
4. Christopher M. *Benchmarks to improve end-of-life care*. Kansas City, Missouri: Midwest Bioethics Center, 2000.
5. [http://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/ac14.pdf](http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ac14.pdf). Accessed on November 25, 2012.
6. Jerant AF, Azari RS, Nesbitt TS, Meyers FJ. The TLC model of palliative care in the elderly: preliminary application in the assisted living setting. *Ann Fam Med* 2004;2:54-60.
7. Reuben DB, Rosen S. Principles of geriatric assessment. In: Halter JB, Ouslander JG, Tinetti ME, et al., eds. *Hazzard's Principles of Geriatric Medicine and Gerontology*, 6th Ed. New York: McGraw-Hill, 2009.
8. Institute for Clinical Systems Improvement (ICSI). *Health Care Guideline: Palliative care*. Bloomington (MN): Institute for Clinical Systems Improvement (ICSI), 2011.
9. Bernabei R, Venturiero V, Tarsitani P, Gambassi G. The comprehensive geriatric assessment: when, where, how. *Crit Rev Oncol Hematol* 2000;33:45–56.
10. Scanlan BC. The value of comprehensive geriatric assessments. *Care Manag J* 2005;6(1):2-8.
11. Wieland D, Hirth V. Comprehensive Geriatric Assessments. *Cancer control* 2003;10(6):454-462.
12. <http://www.who.int/cancer/palliative/definition/en/>. Accessed on December 13, 2012.
13. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. *J Public Health Med* 1997;19(2):193-199.
14. Extermann M, Hurria A. Comprehensive geriatric assessments for older patients with cancer. *J Clin Oncol* 2007;25(14):1824-1831.
15. Stiel S, Pastrana T, Balzer C, et al. Outcome assessment instruments in palliative and hospice care – a review of the literature. *Support Care Cancer* 2012;20:2879-2893.
16. Mularski RA, Dy SM, Shugarman LR, et al. A systematic review of measures of end-of-life care and its outcomes. *Health Serv Res* 2007;42(5):1848-1870.
17. Parker D, Dodgkinson B. A comparison of palliative care outcome measures used to assess the quality of palliative care provided in long-term care facilities: a systematic review. *Palliat Med* 2011;25:5.
18. Van Soest-Poortvliet MC, van der Steen JT, Zimmerman S, et al. Measuring the quality of dying and quality of care when dying in long-term care settings: a qualitative content analysis of available instruments. *J Pain Symptom Manage* 2011;42(6):852-863.



19. Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Ann Intern Med* 2009;151:264-269, W64.
20. <http://www.nationalconsensusproject.org/guideline.pdf>. Accessed on November 5, 2013.
21. Schwartz CE, Merriman MP, Reed G, Byock I. Evaluation of the Missoula-VITAS Quality of Life Index – Revised: research tool or clinical tool? *J Palliat Med* 2005;8(1):121-135.
22. Chan H, Pang SMC. Applicability of the modified Quality-of-Life Concerns in the End of Life Questionnaire (mQOLC-E) for frail older people. *Asian J Gerontol Geriatr* 2008;3:126-132.
23. Sterkenburg CA, King B, Woodward CA. A reliability and validity study of the McMaster Quality of Life Scale (MQLS) for a palliative population. *J Palliat Care* 1996;12(1):18-25.
24. Declercq A, Gosset C, Paepen B et al. *Actieproject BelRAI II: Haalbaarheid van de RAI-methode in België*. Leuven: LUCAS, 2008.
25. Bernabei R, Landi F, Onder G et al. Multidimensional geriatric assessment. Second and third generation assessment instruments: the birth of standardization in geriatric care. *J Gerontol A Biol Med Sci* 2008;63A:308–313.
26. <http://belrai.org/>. Accessed on July 16, 2013.
27. Carpenter GI, Challis D. A thread from many strands: Assessment, the interRAI MDS system, and health and social care policy in England and Wales. In: Fahey C, Fries B, eds. *Implementing the resident assessment instrument: case studies of policymaking for long-term care in eight countries*. New York: Milbank Memorial Fund, 2003.
28. Phillips CD, Morris JN, Hawes C, et al. Association of the Resident Assessment Instrument (RAI) with changes in function, cognition, and psychosocial status. *J Am Geriatr Soc* 1997;45(8):986-993.
29. Brant BE, Hawes C, Morris JN, et al. Effect of the National Resident Assessment instrument on selected health conditions and problems. *J Am Geriatr Soc* 1997;45(8):994-1001.
30. Schnelle JF. Can nursing homes use the MDS to improve quality? *J Am Geriatr Soc* 1997;45(8):1027-8.
31. Hawes C, Mor V, Phillips C, et al. The OBRA-87 nursing home regulations and implementation of the resident assessment instrument effects on process quality. *J Am Geriatr Soc* (1997);45:977–985.
32. Steel K, Ljunggren G, Topinková E, et al. The RAI-PC: an assessment instrument for palliative care in all settings. *Am J Hosp Palliat Care* 2003;20:211-219.
33. Hirdes J, Ljunggren G, Morris JN, et al. Reliability of the interRAI suite of assessment instruments: a 12-country study of an integrated health information system. *BMC Health Serv Res* 2008;8:277.
34. Smith TF, Steel K, Fries BE, et al. *interRAI Palliative Care (PC) assessment form and user's manual*, version 9.1. Washington DC: interRAI, 2010.
35. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Qual Health Care* 1999;8:219-227.

36. Brandt BE, Deliens L, van der Steen JT, et al. The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale. *Palliat Med* 2005;19:334-342.
37. Siegert JR, Gao W, Walkey FH, Higginson IJ. Psychological well-being and quality of care: a factor-analytic examination of the palliative care outcome scale. *J Pain Sym Man* 2010;40(1):67-74.
38. Hawes C, Morris JN, Phillips CD, et al. Reliability estimates for the minimum data set for nursing home resident assessment and care screening (MDS) *Gerontologist* 1995;35:172.
39. Morris JN, Nonemaker S, Murphy K, et al. A commitment to change: revision of HCFA's RAI. *J Am Geriatr Soc* 1997;45:1011–1016.
40. Fries BE, Simon SE, Morris JN, et al. Pain in U.S. nursing homes: Validating a pain scale for the Minimum Data Set. *Gerontologist* 2001;41:173–179.
41. Koehler M, Rabinowitz T, Hirdes J, et al. Measuring depression in nursing home residents with the MDS and GDS: An observational psychometric study. *BMC Geriatrics* 2005;5.
42. Mor V, Angelelli J, Jones R, et al. Inter-rater reliability of nursing home quality indicators in the U.S. *BMC Health Services Research* 2003;3:1.
43. Morris JN, Jones RN, Fries BE, Hirdes JP. Convergent validity of minimum data set-based performance quality indicators in postacute care settings. *American Journal of Medical Quality* 2004;19:242.
44. Morris JN, Fries BE, Steel K, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc* 1997;45:1017–1024.
45. Landi F, Tua E, Onder G, et al. Minimum data set for home care: A valid instrument to assess frail older people living in the community. *Medical Care* 2000;38:1184–1190.
46. Hawes C, Fries BE, James ML, Guihan M. Prospects and pitfalls: Use of the RAI-HC assessment by the Department of Veterans Affairs for home care clients. *Gerontologist* 2007;47:378–387.
47. Carpenter GI, Teare GF, Steel K, et al. A new assessment for elders admitted to acute care: Reliability of the MDS-AC. *Aging (Milano)* 2001;13:316–330.
48. Kim A, Fall P, Wang D. Palliative care: optimizing quality of life. *J Am Osteopath Assoc* 2005;105(11 Suppl 5):S9-14.

## TABLE AND FIGURE LEGENDS

**Table 1.** Medical Subject Headings (MeSH) Search Terms

**Table 2.** Summary of Studies Evaluating CGAs for Nursing Home Residents near the End of Life  
MVQOLI-R = Missoula-VITAS Quality of Life Index – Revised; mQOLC-E = modified Quality of Life Concerns in the End of Life Questionnaire; MQLS = McMaster Quality of Life Scale; InterRAI PC = InterRAI Palliative Care; POS = Palliative care Outcome Scale.

**Table 3.** Validated CGAs for Nursing Home Residents with Palliative Care Needs

MVQOLI-R = Missoula-VITAS Quality of Life Index – Revised; mQOLC-E = modified Quality of Life Concerns in the End of Life Questionnaire; MQLS = McMaster Quality of Life Scale; PWD = People With Dementia; PWOD = People Without Dementia; QOL = Quality Of Life; RHS = Ryff Happiness Scale; MSAS = Memorial Symptom Assessment Scale (MSAS); P-ADL = Physical Activities of Daily Living; I-ADL = Instrumental Activities of Daily Living; CIRS = Cumulative Illness Rating Scale; SIS = Single Item Scale; SQLI = Spitzer Quality of Life Index; InterRAI PC = InterRAI Palliative Care; POS = Palliative care Outcome Scale.

**Table 4.** Content Analysis of CGAs for Nursing Home Residents Receiving Palliative Care Based on the Guidelines for a Palliative Approach to Residential Aged Care (AGDHA)<sup>5</sup>

MVQOLI-R = Missoula-VITAS Quality of Life Index – Revised; mQOLC-E = modified Quality of Life Concerns in the End of Life Questionnaire; MQLS = McMaster Quality of Life Scale; InterRAI PC = InterRAI Palliative Care; POS = Palliative care Outcome Scale.

**Figure 1.** PRISMA flow diagram

CGAs = Comprehensive Geriatric Assessments

## **LIST OF ABBREVIATIONS**

AGDHA: Australian Government Department of Health and Ageing

CGAs: Comprehensive Geriatric Assessments

TIME: Toolkit of Instruments to Measure End-of-life care

WHO: World Health Organization

MeSH: Medical Subject Headings

InterRAI PC: InterRAI Palliative Care

MDS: Minimum Data Set

CAPs: Clinical Assessment Protocols

QIs: Quality Indicators

MVQOLI: Missoula-VITAS Quality of Life Index

MVQOLI-R: Missoula-VITAS Quality of Life Index-Revised

POS: Palliative care Outcome Scale

QOLC-E: Quality of life Concerns in the End of Life Questionnaire

mQOLC-E: Modified Quality of Life Concerns in the End of Life Questionnaire

MQLS: McMaster Quality of Life Scale

PWD: People With Dementia

PWOD: People Without Dementia

QOL: Quality Of Life

RHS: Ryff Happiness Scale

MSAS: Memorial Symptom Assessment Scale (MSAS)

P-ADL: Physical Activities of Daily Living

ADL: Activities of Daily Living

I-ADL: Instrumental Activities of Daily Living

CIRS: Cumulative Illness Rating Scale

SIS: Single Item Scale

SQLI: Spitzer Quality of Life Index

Table 1

Medical Subject Headings (MeSH) Search Terms\*

Search category	MeSH terms
Comprehensive	Comprehensive Health Care; Delivery of Health Care; Spirituality; Signs and Symptoms; Psychology
Geriatric	Aged
Assessment	Instrumentation; Data Collection; Needs assessment; Outcome and Process Assessment; Patient Care Planning; Self-Assessment
Palliative Care	Palliative Care <sup>a,b</sup>
Nursing Homes	Long-Term Care Facilities; Residential Facilities; Geriatric Nursing

\* For a detailed table with MeSH terms, keywords and explosions of the search strategy, please contact the authors.

<sup>a</sup> Since the meaning of 'hospice' differs across countries, the MeSH term 'Hospice Care' was not included in our search strategy.

<sup>b</sup> The MeSH term 'Terminal Care' was also not included in our search string as our focus was on geriatric assessments at the initiation of palliative care needs and not during the last days of life.

**Table 2**  
Summary of Studies Evaluating CGAs for Nursing Home Residents near the End of Life

Author, Year	Instrument	Study design	Age, Mean ± Standard Deviation	Sample Size	Population of validation process
Schwartz et al., 2005 <sup>21</sup>	MVQOLI-R	Cross-sectional study and longitudinal study	66.3 ± 14.6	175	Massachusetts, New York, Florida
Chan & Pang, 2008 <sup>22</sup>	mQOLC-E	Cross-sectional study	82.5 ± 6.7	313	Hong-Kong
Sterkenburg et al., 1996 <sup>23</sup>	MQLS	Descriptive validation study	65 ± 15.5	84	England
Steel et al., 2003 <sup>32</sup>	InterRAI PC	Descriptive validation study	79 ± 11	144 patients across different settings. 47 participants (33%) were from nursing homes	Czech, Sweden, United States
Hirdes et al., 2008 <sup>33</sup>	InterRAI PC	Descriptive validation study	<65: 10.4 65-84: 60.4 85: 29.2	126	Czech, Iceland, Norway, Spain, United States
Brandt et al., 2005 <sup>36</sup>	POS	Qualitative study: prospective nationwide observational study	83.7 ± 8	328	The Netherlands
Siebert et al., 2010 <sup>37</sup>	POS	Factor analyses of two POS data sets	Sample 1: 70.5 ± 12.1 Sample 2: 64.8 ± 12.7	Sample 1: 132 Sample 2: 99	Britain

**Abbreviations:** MVQOLI-R = Missoula-VITAS Quality of Life Index – Revised; mQOLC-E = modified Quality of Life Concerns in the End of Life Questionnaire; MQLS = McMaster Quality of Life Scale; InterRAI PC = InterRAI Palliative Care; POS = Palliative care Outcome Scale.

Table 3

Table 3  
Validated CGAs for Nursing Home Residents with Palliative Care Needs

Instrument	Items	Scale	Reliability			Validity		Sensitivity to change	Filled out by	Completion time
			Internal consistency	Test-retest	Rater	Construct validity	Concurrent validity			
MVQOLI-R	15 items	5-point Likert scale	Cronbach's $\alpha$ = 0.71  Cronbach's $\alpha$ of the five subscales: $r$ = 0.23-0.70	Test-retest reliability for the total score: $r$ = 0.77  Intra-class correlation coefficient for the five subscales: $r$ = 0.59-0.70	Between-subjects coefficient and within-subjects coefficient are similar (-0.023 and -0.022) ( $p$ = 0.000)	$r$ = 0.35 with QOL  $r$ = 0.47 with RHS  $r$ = -0.35 with symptom burden  $r$ = 0.46 with mood	Not available	The total score on the MVQOLI-R has an impact on global symptom related distress after adjusting for mood	Staff or patient	Not available
mQOLC-E	23 items	4-point Likert scale	Cronbach's $\alpha$ = 0.89  Cronbach's $\alpha$ of the six subscales: $r$ = 0.71-0.86	Not available	$r$ = 0.83	$r$ = 0.28 with P-ADL  $r$ = 0.22 with I-ADL  $r$ = 0.14 with CIRS	$r$ with overall quality of life SIS = 0.60 ( $p \leq 0.001$ )  $r$ with CIRS = -0.14 ( $p$ = 0.013)	Sensitivity cannot be assumed as conclusions were drawn from a cross-sectional study	Not available	20-60 minutes

Instrument	Items	Scale	Reliability			Validity		Sensitivity to change	Filled out by	Completion time
			Internal consistency	Test-retest	Rater	Construct validity	Concurrent validity			
<b>MQLS</b>	32 items	7-point numerical scale	Cronbach's $\alpha$ = 0.80	Not available	Patient: $r$ = 0.84 Family: $r$ = 0.95 Staff: $r$ = 0.83	Verbally administered scores are lower than scores of self-completers: $t$ = 1.83 ( $p$ = 0.04)	$r$ between SQLI and staff-MQLS = 0.70  $r$ between SQLI and patient-MQLS = 0.50	Patients who rated themselves as improved, not changed or deteriorated differed in the amount of change they reported in the MQLS	Staff or patient	3-30 minutes
<b>InterRAI PC</b>	74 items	Ordinal scale	Not available	Not available	Inter-rater reliability > 0.77 in all domains (Mean Kappa = 0.83). Kappa $\geq$ 0.80 for 50 percent of the questions	Not available	Not available	Not available	InterRAI is filled out multi-disciplinary by the healthcare team	20 minutes



Instrument	Items	Scale	Reliability			Validity		Sensitivity to change	Filled out by	Completion time
			Internal consistency	Test-retest	Rater	Construct validity	Concurrent validity			
POS	10 items	5-point Likert scale (items 1-8) and 3-point Likert scale (items 9-10)	Not available	Not available	Not available	Not available	Not available	Not available	The POS-staff version is completed by the staff (nursing home physicians, nurses, etc.) and the POS-patient version is completed by the patient.	10 minutes

**Abbreviations:** MVQOLI-R = Missoula-VITAS Quality of Life Index – Revised; mQOLC-E = modified Quality of Life Concerns in the End of Life Questionnaire; MQLS = McMaster Quality of Life Scale; PWD = People With Dementia; PWOD = People Without Dementia; QOL = Quality Of Life; RHS = Ryff Happiness Scale; MSAS = Memorial Symptom Assessment Scale (MSAS); P-ADL = Physical Activities of Daily Living; I-ADL = Instrumental Activities of Daily Living; CIRS = Cumulative Illness Rating Scale; SIS = Single Item Scale; SQLI = Spitzer Quality of Life Index; InterRAI PC = InterRAI Palliative Care; POS = Palliative care Outcome Scale.

Table 4

**Table 4**  
Content Analysis of CGAs for Nursing Home Residents Receiving Palliative Care Based on the Guidelines for a Palliative Approach to Residential Aged Care (AGDHA)<sup>5</sup>

Domains	Content	MVQOLI-R	mQOLC-E	MQLS	POS	InterRAI PC (Version 9.1)
1. Palliative care models and practices	Determination of prognosis and survival time, transfers or discharges of residents, members of the multidisciplinary team	-	-	-	2 items - Addressing practical matters (financial/personal) - Information provided to patient and family	9 items - Reason for assessment - Type of palliative program - Prognosis - Assessment reference date - Time since last hospital stay - Date palliative program began - Palliative treatment programs - Hospital and emergency room use - Date of discharge - Discharged to
2. Assessment and management	Evaluation and treatment of pain and	Assessment tool	Assessment tool	Assessment tool	Assessment tool	Assessment and management tool

tools

other problems,  
physical,  
psychological,  
spiritual

3.	Co-morbidities	Assessment of comorbidities (cancer, heart failure, Parkinson's Disease, Chronic Obstructive Pulmonary Disease, ...)	-	-	-	-	2 items
							- Other disease diagnosis
							- Medications
4.	Cognitive impairment	Assessment of dementia (care), confusion, behavioral and psychological symptoms	-	-	2 items	-	5 items
					- Confusion		- Cognitive skills
					- Concentration		- Consciousness
							- Memory
							- Disordered thinking
							- Mental status
5.	Physical care	Assessment and management of physical symptoms: fatigue, cachexia, dysphagia, mouth care, skin integrity, bowel care, hydration, etc.	5 items	5 items	16 items	2 items	21 items
			- Symptom control	- Second most troublesome	- Pain	- Pain	- Pain
			- Feeling sick		- Appetite	- Other symptoms (nausea, coughing, constipation)	- Dyspnea
			- Symptom acceptance	- Third most troublesome	- Insomnia		- Fatigue
			- Symptom control		- Nausea		- Falls
			- Physical discomfort	- Third most troublesome	- Restlessness		- Recent falls
				- General physical discomfort	- Breathing		- Problem frequency
				- Most	- Pain		- Tobacco and alcohol
					- Diarrhea		
					- Vomiting		

				troublesome discomfort	<ul style="list-style-type: none"> <li>- Cough</li> <li>- Edema</li> <li>- Constipation</li> <li>- Sore mouth</li> <li>- Fatigue</li> <li>- Mobility</li> <li>- Drowsiness</li> </ul>		<ul style="list-style-type: none"> <li>- Height and weight</li> <li>- Nutritional issues</li> <li>- Mode of nutritional intake</li> <li>- Self-reported intake</li> <li>- Most severe pressure ulcer</li> <li>- Prior pressure ulcer</li> <li>- Skin ulcer (other)</li> <li>- Major skin problems</li> <li>- Skin tears or cuts</li> <li>- Other skin conditions</li> <li>- Hearing</li> <li>- Distance wheeled self</li> <li>- Physical function improvement</li> <li>- Allergy to any drug</li> </ul>
6.	Psychosocial support	Assessment of depression, anxiety, confusion, social support, intimacy and	4 items <ul style="list-style-type: none"> <li>- Dependent on others</li> <li>- Ability to say</li> </ul>	8 items <ul style="list-style-type: none"> <li>- Nervous</li> <li>- Low mood</li> <li>- Sad</li> </ul>	3 items <ul style="list-style-type: none"> <li>- Mood</li> <li>- Anxiety</li> <li>- Well-being</li> </ul>	1 item <ul style="list-style-type: none"> <li>- Anxiety (patient)</li> </ul>	2 items <ul style="list-style-type: none"> <li>- Depressed, anxious or sad mood</li> </ul>

sexuality	things to close	- Worried	(calm/relaxed)	- Self-reported mood
	people	- Lonesome		
	- Feeling closer to others	- Powerless		
	- Having close personal relationships	- Helpless		
		- Hopeless		

7. Spiritual support	Assessment of spiritual needs: religious beliefs, pastoral care, coping behaviors, etc.	5 items	3 items	1 item	1 item	2 items
		- Feeling disconnected	- Feels that life is meaningful	- Meaning of life	- Value of life	- Life completion
		- Meaning in life	- Feels that life is worthwhile			- Self-reported spirituality
		- Comfortable with thought of death	- Feels that life is a gift			
		- Value of life				
		- Meaning of life				
8. Family/carer support	Family involvement in end-of-life treatment decisions and family assistance with physical care needs and communication  Emotional support to family members	2 items	3 items	4 items	2 items	6 items
		- Satisfaction with relationships with friends and family	- Feels a burden to others	- Interest in others	- Ability to share feelings with family or friends	- Formal care
		- Spending time with family and friends	- Feels that health care providers can meet his/her needs	- Social interaction		- Living arrangement
			- Feels supported	- Self care	- Anxiety (family)	- Time with person
				- Decision making		- Informal helpers
						- Hours of informal care
						- Informal helper status
9. Indigenous support	Assessment of aboriginal status	-	-	-	-	1 item
						- Ethnicity and

race						
10. Cultural issues	Asking for information on culture and language	-	-	-	-	1 item - Primary language
11. Advance care plans	Assessing the presence of advance care plans which elicit the person's wishes regarding treatment decisions which will guide decision-making when the person is incompetent of doing so	2 items - My affairs are not in order - Feeling prepared to leave life	-	1 item - Future planning	-	4 items - Expressed goals of care - Legal responsibility - Advance directives - Person's wishes
12. Dignity and quality of life	Assessment of factors that contribute to the person's sense of dignity and quality of life: sense of control, relationships with loved ones, capacity to communicate, being continent, pain management, avoiding inappropriate	7 items - Overall quality of life - Satisfaction with oneself - Worrying about things getting out of control - Peace with oneself - Satisfaction with ability to take care of basic	4 items - Feels good about him/herself as a person - Satisfied with overall health care received - Perceives the world as full of love and caring - Satisfied with the food provided	3 items - Appearance - Personal comfort - Overall quality of life	2 items - Feeling good about yourself as a person	9 items - Change in ADL - Bladder continence - Urinary collection device - IADL self-performance - ADL self-performance - Bowel continence - Decision making

	prolongation of dying	-	needs			-	Making self understood
		-	Acceptation of ability to do things			-	Understand others
		-	Contentment with life				
13. Rural and remote issues	Information on isolated and remote sites (country, rural, distant, etc.)	-	-	2 items	-	5 items	
				- Employment		- Residential/living status	
				- Household management			
Other domains (not part of the AGDHA framework)		-	-	-	-	7 items (identification items)	
						- Name	
						- Gender	
						- Birthdate	
						- National numeric identifier	
						- Agency provider number	
						- Current payment resources	
						- Postal/ZIP code of usual living arrangement	

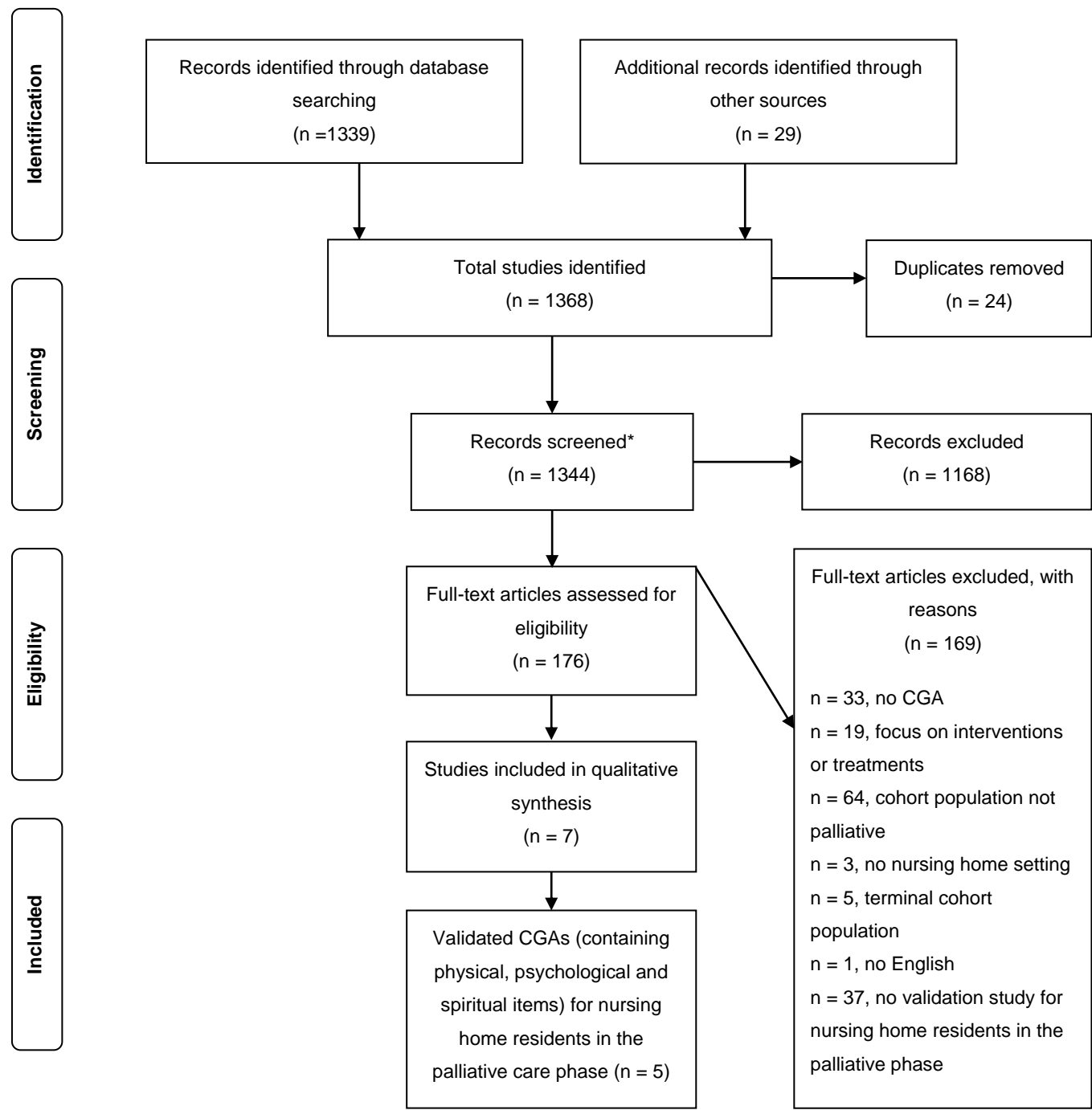


Figure 1. PRISMA flow diagram

\*Based on title (1172) or abstract (n = 172)